DATA DEVELOPMENT SUBCOMMITTEE DRAFT MINUTES
April 1, 2019 – 12:00 PM
Smyrna State Service Center, Smyrna, DE

QUORUM 5 OF 7 MET

PRESENT: Karen **McGloughlin**, Director of Women's Health, **CHAIR**; Christine **Applegate**, EN Navigator, Bayhealth; Andrew **Burdan**, Brain Injury Advocate/Support Group; Brian **Eng**, Esquire, Community Legal Aid Society, Inc., Disabilities Law Program; Nicholas **Duko,** Program Manager, LTSS, BCBS Highmark Health Options; and Dee **Rivard**, SCPD Support.

ABSENT: Thomas **Cairo**, Bayhealth Neurosurgery; Ann **Phillips**, Parent of a survivor;

GUESTS: (Not able to vote or count toward quorum)

IN-PERSON – Randall J. Farmer, COO and Terri Lynn Palmer, Delaware Health Information Network (DHIN); DHIN website: https://dhin.org/

TELECONFERENCE PARTICIPANTS: None

CALL TO ORDER

Christine Applegate called the meeting to order at 12:12 p.m., thanking Mr. Farmer and Ms. Palmer from Delaware Health Information Network for attending today's meeting to provide additional information.

NEW BUSINESS – DHIN Presentation

Christine told Mr. Farmer and Ms. Palmer what kind of information the subcommittee was looking to obtain from DHIN and why requesting him to go ahead and start his presentation.

- Mr. Farmer advised that DHIN currently receives information from 3 Acute-Care Hospitals in Delaware, along with all of the hospitals in MD, NJ, D.C., PA, and VA, reporting clinical and lab information to their system. Information that they receive includes admissions instructions and transfer reporting. If someone was treated in Delaware for a brain injury whether or not they live in Delaware, DHIN will have that information. DHIN is able to provide frequency of occurrence by zip code, county, gender and age group and the information that they receive is not PI protected information. DHIN is able to provide 3 – 4 years' worth of information for comparison depending on what this subcommittee requests.
- Christine advised that she is looking for information on what they would need to request whether it be by ICD-10 codes or other information for inclusion and exclusion criteria asking if it is possible for the subcommittee to scope out DHIN data in order to see how

much information it already has that the BIC needs and what additional information this subcommittee will need to request for our needs.

- Karen inquired as to what kind of data DHIN is already collecting.
    - Randy advised that DHIN would have the kind of information this subcommittee is looking to receive; however, they would need to know the terms of collection frequency the subcommittee is looking to receive the data. DHIN will not have a problem supplying all of the necessary data since they are not providing any kind of PII. All DHIN needs are the inclusion and exclusion requests in order to manipulate the data to provide us with the cost of services. However, from what he is hearing from subcommittee members; he feels safe in stating that we would be looking at between $1,000.00 to $5,000 based on the lift required to do our specific query and to QA the query. If there is no real material difference necessary for subsequent updates, DHIN could just run the same query on subsequent reports which would run approximately $1,000 annually.
    - Ms. Palmer advised that the data is going to help make decisions and let members know what you have and what you don't have in order to plan ahead. This project could do a study once and then create a future plan. She advised that traditionally registries are built by the provider providing the service and then sent off to the master body that is receiving the information. However, there is no need to bother requesting information from individual providers so long as the registry data information is part and parcel of the existing information that is already received by DHIN.
- Karen expressed her concern with the information that is being provided to DHIN questioning how many layers the hospitals' drill down when providing information. For example, a patient could arrive to the emergency department with a heart attack who may also have a TBI that was obtained as a result of falling or crashing in a vehicle during the heart attack. Are providers reporting secondary, third, and fourth injuries or just the primary reason for treatment?
    - Randy stated that the information DHIN receives is pretty robust. That is the benefit of having a centralized community health record. It is primarily stipulated to have that record information. That is the he nature of our business and DHIN is uniquely positioned to drill down on the data, get lab results, and radiological

studies. DHIN receives data from all hospitals and labs in the State of Delaware and 95% of commercial radiological centers. DHIN also has connections with hospitals who border Delaware and Maryland, including Union Hospital, Salisbury, Baltimore, and Berlin. In addition to having connections with counterparts in the Health Information Exchanges (HIE) in NJ. If a DE resident is treated in one of those centers they get an ADT on that patient. The Health Services Exchange (HSE) in PA reports encounters with Delaware residents to DHIN. MD, D.C. VA, and one hospital in Ohio also report to DHIN. There are over 150 known clinical messages reported to DHIN. Randy's father suffered a severe TBI 20 years ago with damage to his frontal lobe from the recoil. He considers this topic near and dear to his heart. If they receive inclusion criteria that includes ICD-10 codes as well as other types of key phrases and narratives that they can search, DHIN can cast a pretty strong net. They can put it together in zip code level in CSV or Excel Spreadsheet format and they also do mapping.

- Karen inquired if the data can be layered to take a population of a certain age group and then map it by county or zip-code?
    - Ms. Palmer shared that claims data will include whether a particular injury type occurred and if the payment provider paid the invoice for treatment. She explained that the clinical data is reserved for actual providers. DHIN is not a provider they are a 3rd party business. However, by approaching the claims data there is a form DHIN uses to starts the ball rolling for agreements before an entity receives data. The initial project start might include some mapping details of who is where using a tool called Tableau. This would allow the BIC to see classifications by age group, patients who came from out of state, etc. The data set is de-identified so you cannot determine who is who. It will enable the BIC to see the big picture including where needs are and where patients are receiving treatment currently. DHIN data can show where an individual lives by zip-code and where they receive their services. All of this information is already in the claims data. There is so much more detail that is available in the claims data to obtain.
- Karen expressed a concern that as far as incidence data not everyone completes a claim.

    - Ms. Palmer advised that while DHIN already has Medicaid, Medicare, and State Related Program Pay information they are missing private insurance. She stated that by the time DHIN gets extracted data they could also assist with analyzing the data.
- Karen stated that the clinical information would be a great supplement and questioned how much information could the BIC pull from the clinical information since neither the BIC nor the DDS are service providers.
    - Randy advised that since DHIN is not including any kind of personally identifiable information that it will enable the BIC to pull a lot of information from the clinical data.
- Karen advised that the BIC is looking to get as close as they can to learning how frequently brain injuries are occurring in Delaware.
    - Randy advised that he will go back and talk to DHINs Council. He stated that it could prove very interesting to have the claim information included in order to see frequency related data. E.g. Length of treatment, subsequent injuries, etc.
    - Ms. Palmer recommended that the BIC pull information from both data sets in order provide better information.
- What about the corner docs in a box?
    - Randy shared that DHIN is already receiving information from Med Express, Ambient Urgent Care and Newark Care Express. However, there are still at least 100 other non-hospital related ambulatory care organizations that DHIN is working to obtain information from.
- Is it safe to assume that if a patient with a brain injury visited a Med-Express or similar facility that they would probably receive a referral to an Acute Care Center?
    - Randy advised that if the patient had an ABI or TBI they would refer since they do not have the MRI or CAT scan equipment on-site.
    - Ms. Palmer stated that DHIN already collects data from radiology locations throughout Delaware.
    - Randy shared that he recently received a copy of draft regulation (legislation) that specifically spelled out the definition of an urgent care center.

- If you are not tracking the information you are not able to include it in planning. What about duplications in DHIN data?
    - DHIN tracks patients from emergency departments and hospitals to rehabilitation, to private medical providers. Each organization assigns a patient their own specific patient number from a set of master numbers.
    - DHIN does all the work of tracking all of the various numbers assigned to an individual patient and then assigns all of those numbers to one specific patient individually in order to avoid duplication in reporting data.
    - Once an individual data set is created it is easier to request a refresh of the same data in subsequent years.
    - The first report that DHIN could provide the BIC could go back three years or could go back as far as 2014 through 2018.
    - Terri stated that the BIC could begin by requesting a small time frame and then expand the time frame at a later date.
- Karen stated that once we receive the data it will be interesting to see the trends.
    - Terri explained that since the existing data that the BIC already obtained from the Delaware Trauma System Registry is from 2014 through 2017 there is no sense going back further.
    - Terri advised that DHIN needs subset of TBIs and then to add additional columns.
    - Terri recommended that DHIN just replicated the same information as requested for TBIS to add the same thing to run the data for ABIs.
- Is there a lag with the data?
    - Clinical data is received in almost real-time. The claims data received every month is from 2 months ago for adjudicated claims. Usually claims are paid within 190 days. If it was wholly denied it will not show up on the claims data. Theoretically DHIN should receive all of 2018 by the end of June. Karen stated that for the Division of Public Health there are certain areas that they focus on and DDS wants to get a broader look.
    - Terri stated that just taking a quick glance at the data provided from the Delaware Trauma Systems Registry, it appears that 50% of the TBIs occur in people 50

years-of-age and older. It will be interesting to see what impact treatment might have on these statistics.

- Karen is a Preventionist stating that it will help to know where to focus more education and prevention on that particular area. She would also be interested in knowing about reoccurrences. For instance if a child is identified with a TBI in the 6th grade and continues to participate in athletic activities doing the same thing year after year there is a cumulative effect.
- Christine suggested that the data could help with thoughts on where to focus educational needs since education is the number one preventative measure. The BIC wants to see trends. Are brain injuries getting worse because patients are not getting the proper treatment that they need?
    - Terri stated that DHIN can follow individuals over time. Might still be able to do this using metadata. Do you want frequency of reoccurrences? What about by given school district. Oversight? What degree of resources are being utilized? What about maximization of therapy and resources?
    - Randy mentioned Inter-agency agreements that will allow for greater utilization of claim information. SB 238 in 2016 specifically named DHSS, DHCC, OMB, now DHR and one other department that he could not think of off the top of his head. Randy shared that a lot of agencies think that DHIN is a state agency; however, it is not a State Agency. DHIN is codified as an entity that operates as an independent non-profit. DHIN does not receive funding from the state. DHSS purchases approximately $40,000 worth of services and DHIN has a 9 million dollar budget.
- Dee agreed to send Ms. Palmer a copy of the TBI data from Delaware Trauma System Registry.
- Karen agreed to assemble and submit exclusion and inclusion criteria.
    - Randy believes that the BIC and the Data Development Subcommittee will really receive a great value from having DHIN pull together the necessary information for a Brain Injury Registry.
    - Terri advised that there is a whole lot to describing extract in how BIC may want to differentiate individuals from what DHIN already has and the data that DDS

has from the Delaware Trauma Registry. Does BIC only want the same ICD-10 codes wherever they fall? Do you want the ability to isolate and count per individual as opposed to counting the claims that come-in? The groupers are something that DHIN could obtain easily e.g., race, age, county etc. Don't hold up your ask for trying to be very detailed.

- Karen likes the idea of having some sort of website to look at this.
    - Randy and Terri both suggested starting small and then increasing similar to a crawl, walk, and run type of situation. DHIN can give access to their analytic tool and then add the extracted data behind it. This is running as opposed to the crawling. Terri suggested that at some time in the future DHIN could possibly empower the BIC with its own feed of data; of course the financial ask would be larger. DHIN would buy 100 licenses and then BIC would have 1 license. Doing it this way results in a much lower cost as an annual feed because it only requires maintenance energy.
- DDS members are excited about the possibility of just being able to see the services that are needed in Delaware as a result of having access to the data.
- Karen mentioned that to be able to have a state administrator monitoring incidences of brain injuries would greatly benefit Delawareans. Right now the information doesn't sit in any one agency. If the Data Development Subcommittee and the BIC could get to that point in order to see if there is an uptick in a certain geographic area or during specific large events it would be huge.
    - Randy - DSAMH benefits from smart alert data in real-time. They receive data as a provider to Social Service; however, in the Brain Injury Committee's place, receipt is more for coordination of care. Advancements in terms of technology are enabling us to exploit the power of data.

NEXT STEPS

- Homework as a subcommittee is to figure out what specific data we are requesting the DHIN to provide.
- Work on developing a list of inclusion and exclusion criteria to submit to DHIN so they can provide a cost estimate for creation of the report.
- Do we want just ICD-10 codes or do we also want to receive ICD-9 codes?

- Do we want to focus on any keyword searches to include such as concussion, mConcussion, sConcussion, brain injury, etc.?
- Do we want to request the same data for ABIs as TBIs or do we want to specifically exclude some data such as anoxic brain injuries or brain injuries from birth?

ADJOURNMENT

- Christine made a motion to adjourn that Nicholas Duko seconded. Karen called for discussion and hearing none, voting subcommittee members present unanimously approved the motion to adjourn.
- With no further business to discuss the meeting adjourned at 1:45 p.m.

NEXT MEETING - Nicholas Duko will send out a meeting notice for the next meeting which is set for **Thursday, April 11 from 2:00 – 3:00 p.m.**